

**Governor's Council on Blindness and Visual Impairment (GCBVI)**  
**Deaf-Blind Issues Committee Meeting Minutes**  
December 5, 2019

**Members Present**

Ed Gervasoni, Chair  
Sue Kay Kneifel  
Megan Mogan  
Jonathan Pringle  
Steve Wilson  
Mary Hartle  
Cindi Robinson  
Larry Rhodes

**Members Absent**

Carmen Green  
Virginia Thompson

**Staff Present**

Lindsey Powers

**Guests Present**

Julie Stylinski, ACDHH  
Dustin McLaws, ASL Interpreter  
Daniel Green, ASL Interpreter  
Debbie Hanlon, CART provider

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**Call to Order and Introductions**

Ed Gervasoni, Chair, called the meeting to order at 10:15 am in the Arizona Commission for the Deaf and Hard of Hearing (ACDHH) Conference Room, Phoenix, AZ. Introductions were made, and a quorum was present.

**Approval of August 15, 2019 Meeting Minutes**

Megan Mogan moved to approve the minutes of the August 15, 2019 Committee on Deaf-Blind Issues meeting. Cindi Robinson seconded the motion. The minutes were approved by unanimous voice vote.

**Chair Report**

Ed Gervasoni stated that he would welcome another council member to join the committee and he would then step down as the Chair of the committee.

Ed Gervasoni stated that he had been part of the council for about 12 years and had joined due to the needs of the deaf-blind community. He added that if any committee members planned to apply for council membership, to let him know. Sue Kay Kneifel stated she spoke to Bob Kresmer, GCBVI Chair, and had expressed the need for deaf-blind members, individuals with combined vision and hearing loss (CVHL) or individuals that represented those populations to join the council.

### **National Deaf-Blind Equipment Distribution Program (NDBEDP) Update**

This item was tabled.

### **SSP Services in Arizona Follow-Up**

Julie Stylinski stated the Arizona Commission for the Deaf and Hard of Hearing (ACDHH) provided 52 Support Service Provider (SSP) hours in September, 76 hours in October, 80 hours in November and would provide approximately 40-50 for December. Julie Stylinski stated she recently completed three more intakes, and noted the program continued to grow through word of mouth. Ms. Stylinski stated ACDHH held a Board Meeting, which approved the copy sign memo that had been distributed to committee members. Julie Stylinski stated ACDHH was waiting to hear back from the State Procurement Office (SPO) regarding the Request for Proposal (RFP) for the SSP contract. Ed Gervasoni inquired when the bidding for the RFP closed. Julie Stylinski stated the bidding for the RFP closed about three weeks prior. Ed Gervasoni inquired whether the RFP included transportation for consumers. Julie Stylinski stated the RFP did include transportation. Mary Hartle inquired regarding the funding for the program. Julie Stylinski stated the program would be funded with the same amount of \$192,000 per year. Mary Hartle inquired when the program would begin. Julie Stylinski stated the program would begin in January or February of 2020. Mary Hartle inquired regarding the vendors that had bid on the contract. Julie Stylinski stated she could not share that information yet. Cindi Robinson inquired regarding the funds that were left over from the previous year, and what happened to those funds. Julie Stylinski stated she was unsure regarding the funds that were left over, but she could get that information. Cindi Robinson stated she would be interested to know whether any funds were carried over to the next year, or whether any funds had been given back. Julie Stylinski stated for the current Fiscal Year, the ACDHH still had funds left. She noted that many individuals did not use the program, likely due to the lack of transportation for consumers. Cindi Robinson inquired regarding the number of SSP service hours that were provided in Tucson. Julie Stylinski stated the majority of SSP hours

were provided in Phoenix. Ms. Stylinski stated that she would be going to Tucson and would be interested in seeing any individuals interested in the program. Cindi Robinson stated there were individuals in Tucson that needed SSP services. Julie Stylinski agreed and noted that she would be pleased to offer services, although individuals needed to reach out to her. Steve Wilson inquired whether consumers completed self-evaluations and whether ACDHH listened to the consumers' feedback. Julie Stylinski stated that SSPs would send her their hours, and they would offer feedback. She noted that consumers would also tell her the hours they received and would offer any feedback. Julie Stylinski stated she would adjust as needed such as getting another SSP for a consumer or providing additional education to SSPs. Steve Wilson stated his concern that consumers were not offering detailed feedback. Julie Stylinski stated as her role as the Deaf-Blind Specialist, she would visit consumers in their homes every six months or more frequently as needed to assess their daily living or to provide case management. She noted that if an individual had concerns regarding their services, she would be welcome them to reach out to her. Cindi Robinson inquired whether the transportation that would be included in the RFP. Julie Stylinski stated the agencies that had their own transportation, such as vans, would provide the transportation, and would bill ACDHH for the services. Ms. Robinson inquired whether ACDHH was contracting with the Community Outreach Program for the Deaf (COPD). Julie Stylinski stated ACDHH did not have a contract with COPD. Ed Gervasoni stated that any agencies, such as COPD, could have bid on the RFP for SSP services.

Ed Gervasoni stated at the last committee meeting, the committee discussed alternate communication methods, such as C-Print, and whether any agencies could provide that communication. Julie Stylinski stated she heard there was a C-Print provider in Tucson, although she had not received a response from that individual. Ed Gervasoni expressed his concern regarding individuals that were not literate enough to keep up with CART. Mr. Gervasoni stated his understanding that an individual could use an ASL interpreter because the individual was translating English to ASL, and CART provided transcription. Julie Stylinski stated she was told that a CART provider could provide the transcription verbatim to the consumer or a summary if that was the consumer's preference. Ed Gervasoni stated that some individuals were able to read Braille, although they were slow readers, and would benefit from a summary of the conversation. He noted that an SSP could not summarize the conversation to a consumer, although a CART provider could potentially provide a summary of the conversation. Julie Stylinski stated that a CART provider could provide a transcription verbatim or a summary or could slow down if the consumer preferred. Ed Gervasoni noted that if a CART provider slowed down their transcription, the consumer would not be receiving the information fast enough to participate in the

conversation. Steve Wilson stated that he had always received CART transcription that was very close to verbatim. Larry Rhodes stated C-Print provided a summary of the conversation, which would allow the individual to keep up with the content. Jonathan Pringle stated there were 2-3 different technologies involved such as CART and a Braille screen reader that would cause a lag in the information as well. Steve Wilson stated that as a consumer, he would not like another individual to decide the content to leave out or summarize. Ed Gervasoni noted that Steve Wilson was fortunate that he was able to keep up with the conversation, although some individuals were not as literate and would benefit from a summary of the conversation. Ed Gervasoni inquired how an individual could participate in a formal meeting if they were unable to keep up with CART. Mary Hartle stated that hearing individuals could speak slower for deaf individuals or individuals with hearing loss. Steve Wilson stated that it should be up to the consumer to decide how they would like to receive the information. Ed Gervasoni agreed that the consumer should decide. Julie Stylinski stated that in any meeting, there could be one team of interpreters providing ASL for one individual and one team of interpreters providing interpretation for an individual with low vision. She noted that there could potentially be a CART provider providing CART verbatim to one individual and another CART provider providing a summary to another individual. Ed Gervasoni inquired how an individual could receive the information if they used a laptop and a Braille display. Julie Stylinski stated that individual would need a typist. Ed Gervasoni inquired whether that would violate interpreter laws. Julie Stylinski stated a SSP could not summarize a conversation, because that would be considered interpreting, and SSPs were not trained typists. Steve Wilson stated that CART services should be combined with SSP services and noted that both were separate services. Ed Gervasoni stated that blind or visually impaired individuals used to use reader/writers, although those positions had been eliminated. He noted there was a need for a third role that could assist in the process. Larry Rhodes stated he would find more information regarding the C-Print typists. Mr. Rhodes stated that universities used to hire C-Print typists to support students, although he was unsure whether those services would be available. Steve Wilson stated that a typist would not have the technology, ethics, or training to provide a conversation verbatim. Ed Gervasoni agreed and stated the committee would look into different communication options.

### **SSP Training Curriculum Update**

Ed Gervasoni inquired whether the RFP for the SSP contract included SSP training. Julie Stylinski stated that one of requirements was that all SSPs would be required to go through ACDHH's SSP training. Larry Rhodes stated that he had volunteered to review the SSP Training Curriculum prior to

implementation and inquired whether that was possible. Julie Stylinski stated she would inquire with the Executive Team of Sherri Collins, Carmen Green, Curtis Humphries and Betty McEntire. Ms. Stylinski stated that she would adjust the Training Curriculum and send them to the Executive Team for approval. Cindi Robinson inquired regarding the revisions that Julie Stylinski was making. Julie Stylinski stated she was waiting to hear back from SPO, and noted once the contract was awarded, the training would begin. Ed Gervasoni inquired regarding the areas that Julie Stylinski was revising. Julie Stylinski stated she was revising the video, which was outdated. She noted that she had reviewed information from the Helen Keller National Center (HKNC). She added that she was also modifying the information that she and Larry Rhodes discussed during the SSP Training. Larry Rhodes stated there were several areas of problematic content and he noted that he would like to review the revisions prior to implementation. Julie Stylinski stated that she would let the Executive Team know. Ed Gervasoni stated that Bob Kresmer had indicated that he had been trying to contact Sherri Collins regarding a collaboration with the GCBVI and the ACDHH on deaf-blind policy changes. Julie Stylinski stated that she would inform Ms. Collins. Steve Wilson stated his concern that blind or visually impaired individuals did not understand the deaf-blind perspective and he would recommend a deaf-blind individual be involved in that discussion.

### **SSP Professional Development and Certification Discussion**

Larry Rhodes stated the American Association of Deaf-Blind (AADB) was developing a White Paper that could have an impact on the SSP training and certification. Mr. Rhodes stated the White Paper would recommend content for the SSP training and he would encourage the ACDHH to review the White Paper. He noted that he was unable to share the White Paper, although it should be available in January. Cindi Robinson inquired regarding the individuals involved in developing the White Paper. Larry Rhodes stated that about seven individuals developed the White Paper, in which about half were deaf-blind. Larry Rhodes stated the White Paper included important content and provided research regarding the cost of SSP support. Cindi Robinson stated her agreement that the committee and the ACDHH should review the White Paper and utilize the information and to work together with the AADB. Julie Stylinski stated she would be interested to read the White Paper as well. Larry Rhodes stated he would forward the White Paper once it was finalized.

### **ACDHH Budget Request Update**

Julie Stylinski stated that she would find out whether any funds had been carried over from the previous year. Mary Hartle inquired whether Julie

Stylinski could share any information with Lindsey Powers, who would distribute to the committee members. Ms. Hartle stated the committee would also be interested in any information regarding the SSP contract.

### **AHCCCS/ALTCS Intervener Services Update**

Ed Gervasoni stated that Dara Johnson was unable to attend the meeting, although she sent him an update. Ed Gervasoni stated the Arizona Health Care Cost Containment System (AHCCCS) was engaged in the final policy team meetings internally and were close to finalizing the assessment tool that would help to determine if an individual needed the services and the number of service hours. He noted that AHCCCS planned to pilot the use of the assessment tool with a few families to observe it in practice. Mr. Gervasoni stated that Dara Johnson expected the policy and tool to go out for public comment in early 2020 and she would send a notice to committee members when the documents were posted. Ed Gervasoni stated he would be interested to know why the process had been delayed. Cindi Robinson inquired regarding the deaf-blind specialist that AHCCCS was working with to develop the assessment tool and policy. Megan Mogan stated that she worked with Dara Johnson to review the assessment tool to provide written scenarios that could be used as examples for individuals piloting the program or individuals involved in the training. Ed Gervasoni stated he reviewed an early rough draft of the assessment tool, which used a lot of intervener information, although he was unsure why it had been delayed.

### **SBVID Report**

Sue Kay Kneifel stated that Brian Dulude had been hired as the SBVID Program Manager. Sue Kay Kneifel stated that if the committee let her know what to report, she would obtain that information for the next meeting. Ed Gervasoni stated he would send Ms. Kneifel the information that the committee would like to know. Mary Hartle inquired whether Brian Dulude had started his position. Sue Kay Kneifel stated that Brian Dulude started his position in September and noted that she would continue to oversee Vocational Rehabilitation (VR) and Dr. Dulude would oversee the Older Individuals Who Are Blind (OIB) and the Business Enterprise Program (BEP).

### **AZ DeafBlind Project Update**

Megan Mogan stated the DeafBlind Project continued to provide outreach and technical assistance activities. She noted the DeafBlind Project hired Amy Trollope as a Part-time staff, whom traveled with another staff member to provide technical assistance to Maricopa county. Ms. Mogan stated that she covered the rest of the state. Megan Mogan stated the DeafBlind Project

would host a workshop with David Brown, an internationally recognized deaf-blind educator, whom specialized working with children with Charge Syndrome. She noted that 27 individuals had registered for the workshop on Friday, and a workshop on Saturday. Megan Mogan stated the registrants spanned across different roles, professions, and family members. Megan Mogan stated the Arizona DeafBlind Project website was available as a standalone site: <https://azdeafblindproject.org/>, which would connect individuals with resources.

### **a. Intervener Trainings**

Megan Mogan stated the Intervener Training continued to work through one module a month for three Intervener Training cohorts. She noted there were 13 individuals in cohort 1, 6 individuals in cohort 2, and 33 individuals in cohort 3. Megan Mogan stated that individuals received face-to-face trainings once a month in addition to the online training.

### **Deaf-Blind Connections in Arizona Update**

Mary Hartle stated the Deaf-Blind Connections in Arizona continued to provide advocacy work with deaf-blind individuals to ensure that individuals received VR services in a timely manner.

### **Workgroup Updates**

Sue Kay Kneifel stated that she spoke to Bob Kresmer regarding the need for deaf-blind representation on the council, and he indicated that the council would support applications from that population. Sue Kay Kneifel stated the workgroup would like to propose changes to the GCBVI Executive Order to identify agencies or individuals that represented the deaf-blind population. Ed Gervasoni agreed that a representative from the ACDHH would help to build the partnership between the council and the deaf-blind community. Mr. Gervasoni noted that would require a change in Legislation. Sue Kay Kneifel stated the council could still encourage deaf-blind or individuals with CVHL to apply for council membership. Julie Stylinski stated if the committee wanted to send her information, she would share the recruitment information with her contacts. Ed Gervasoni stated he would like to see a high school training program that would introduce concepts of deaf blindness into high school programs. Mr. Gervasoni stated the issue was that individuals did not receive a certification upon completion of the training. Larry Rhodes stated he could provide a summary of a meeting with the HKNC regarding certification at the national level, although he agreed that the state should consider certification as well.

## **Conference Updates**

Megan Mogan stated the Charge Syndrome Foundation held an international conference every two years and the next conference would be in Scottsdale in July/August 2021. Jonathan Pringle stated he would submit a proposal to present at the 2020 Association of Persons Supporting Employment First (APSE) Conference in Denver to present with staff.

## **Agenda and Date for Next Meeting**

The next meeting of the Committee on Deaf-Blind Issues was scheduled for March 9, 2020 from 10:00 a.m. to 1:30 p.m. in the Arizona Commission for the Deaf and Hard of Hearing (ACDHH) Conference Room, 100 N. 15<sup>th</sup> Avenue, Suite 104, Phoenix, AZ. Agenda items are as follows:

- Chair Report
- National Deaf-Blind Equipment Distribution Program (NDBEDP) Update
- SSP Services in Arizona Follow-Up
- SSP Training Curriculum Update
- SSP Professional Development and Certification Discussion
- ACDHH Budget Request
- ACDHH Legislative Report
- Deaf-Blind Project Update
- AHCCCS/ALTCS Services Update
- Deaf-Blind Connections in Arizona Update
- Conference Updates

Mary Hartle requested a Legislative update from ACDHH regarding any Legislation pertaining to deaf-blind individuals.

## **Announcements**

There were no announcements.

## **Public Comment**

There was no public comment.

## **Adjournment of Meeting**

Megan Mogan motioned to adjourn the meeting. Sue Kay Kneifel seconded the motion. The meeting was adjourned at 12:18 p.m.